



Community Support

September, 2001

Community Support refers to contributions of formal supports that allow families to participate and be involved and informal support that strengthens the family's ability to thrive and provide care for their child. Research shows that the positive effects of support provided by informal sources generally exceeds the positive effects of support attributed to formal support sources. Working within the formal system, it is obvious that there will never be enough money, enough time, enough professionals to do all that is required when families find themselves living in challenging circumstances.

Formal Support

This refers specifically to how "the system" makes support available.

1. Money

- reimbursement for childcare or to develop childcare capacity
- for personal care attendant (PCA) services to cover meeting time
- funds for stipends, for transportation, reimbursement for phone or other expenses
- payment for responsibility assumed such as editing a newsletter, serving as a parent-to-parent mentor, facilitating a support group, or family support facilitator

2. Flexibility

- meeting at different times or places
- contracting the fiscal host responsibility for the Fiscal Source Code J, or Family Support initiative, to an outside agency in order to;
 - avoid unnecessary procedural delays in reimbursement
 - allow flexibility regarding hiring, job descriptions, and reimbursement

3. Awareness

- promote community and professional awareness of issues families face when raising a child with special needs

Informal Support

Another facet of community support is the way communities, friends, and neighbors network to be of support to individual families. Life changes every day. Sometimes life becomes terribly complex and it is difficult to cope. Under those circumstances, parents often don't get rest, or have the time or emotional energy to tend to the routine details of life. Sometimes life can remain that way for a long time.

Friends, neighbors, relatives, and communities of faith are often invaluable at these times in

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their ability to create a web of support either for the short or long term. It is important to work closely with the family, operating from inside the basis of their personal choice and preference. It is not wise or respectful to make assumptions and proceed without the knowledge or partnership of the family: one family may be very grateful that someone would come in and do their laundry or housecleaning, another would feel violated.

Offer the concrete: “Can I mow your lawn?” “Can I bring you a meal on Tuesday?” “Can I watch your kids Friday after school?” Your contribution could be a donation of some time once, or on a regular basis, so the parent could nap, or have some respite. It might be a fundraising benefit, donations, or a gift of money. It could be ideas. It might mean just being available to listen and do whatever is needed.

The purpose is to provide support. It is not intended to create an unnecessary long-term dependency that enables negative patterns of coping. When approached thoughtfully from the family’s perspective, building and participating with friends and neighbors in an informal network of support can be wonderful and life-affirming, while also providing invaluable resources.

